A Rural Palliative Home Care Model:

The Development and Evaluation of an Integrated Palliative Care Program in Nova Scotia and Prince Edward Island

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(Harvey Chochinov, testimony before the Senate Subcommittee to update "Of Life and Death," February 28, 2000)

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A Rural Palliative Home Care Model:
The Development and Evaluation of an Integrated Palliative Home Care Program in Nova Scotia and Prince Edward Island

A final report for
The Health Transition Fund
Health Canada

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A Note to the Reader

This final report is intended to provide the project highlights viewed as significant in the development, implementation and evaluation of a rural palliative home care model.

The following has not been included in this publication, but is available upon request.

1. Bibliography
2. Evaluation surveys, focus group protocols, results and analysis
3. Education curricula, faculty profiles, and curricula evaluation
4. Program development tools and an information systems needs assessme

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Special thanks go to the Western Health Region in Nova Scotia, which participated as our comparison group in the evaluation strategy, and to their advisory committee and study coordinators.

Thanks to the three demonstration regions: Northern Health Region in Nova Scotia, East Prince Health and Southern Kings Health Regions in Prince Edward Island, for the commitment shown to the project. We cannot stress enough the tremendous human resources the regions have dedicated to this project to ensure its success. The advisory groups and working groups in the regions came from all disciplines and care settings, (from senior management, physicians, and front-line staff) to develop education, service delivery, and evaluation strategies, then met the challenge of implementation with determination and dedication, making the outcomes a rewarding experience.

We cannot express enough appreciation to the front-line staff and palliative care consult/resource teams who were faced with participating in the education sessions, implementing a new integrated program, and recruiting palliative care clients and caregivers to the project's evaluation component, all the while providing excellent palliative care to clients and families. You have been true ambassadors in your support of this project.

Finally, we extend our most sincere thanks to the clients and their caregivers who gave selflessly their time and energy to provide us with their personal insights and knowledge.

Rural Palliative Home Care Project

January 2001

EXECUTIVE SUMMARY

The Rural Palliative Home Care Project was an inter-provincial initiative funded by the Federal Health Transition Fund, to develop, implement and evaluate a palliative care program in three rural communities. Participating regions were the Northern Health Region in Nova Scotia, and East Prince and Southern Kings Health Regions in Prince Edward Island. Western Health Region, Nova Scotia was the comparison region.

Project goals were:

- To increase accessibility to palliative care in rural communities
- To increase support to health care providers and facilitate their increased involvement
- To develop, implement and evaluate an overall education curriculum
- To define the barriers to receiving palliative care in rural communities

These goals were met through the following initiatives:

1. The development and implementation of an integrated program model for palliative care
2. The development and implementation of education curricula delivered to front-line staff and to recently created palliative care resource/consult teams
3. The evaluation of the impact of the new program and education curricula

Prior to the implementation of the new program, demonstration sites indicated that palliative care services to the rural communities were lacking. Specifically, they were fragmented and lacked continuity, void of a common set of operational and evaluation standards, and lacked funding for the palliative home care services and consultation services necessary to support the needs of palliative care patients and their families at home.

1. Integrated Palliative Care Program

The new integrated palliative care programs received a total of 335 referrals in the nine-month data collection period.

The key elements of the integrated palliative care program were:

- Access and referral through a regional single entry point.
- A common palliative care assessment tool and a palliative home chart used collaboratively with all agencies and interdisciplinary team members.
- Coordination through an identified case manager for each client and family and weekly palliative care rounds.
- Care delivery by an interdisciplinary team, in consultation with the palliative care resource /consult team and the patient/family. One demonstration site provided enhancements in nursing, respite and medication coverage.
- Consultation/resource teams that included physicians and nurses and, in some sites, social workers and pharmacists, to provide consultation and leadership in palliative care.
- Community resource linkages to provide support in palliative care volunteerism, support for the acquisition of equipment and support in public awareness.

An information systems needs assessment was conducted to consider the requirements to support an integrated palliative care program with a focus in the home.

2. Education

The education initiative to support the integrated model targeted the multidisciplinary team and the palliative consult teams. There was an overwhelming positive response from participants in their satisfaction with the education program. Front-line recipients demonstrated an increase in knowledge post-test and sustained at three months. The consult teams demonstrated an increase in knowledge in the three-month post-test over the initial post-test.

3. Evaluation

The evaluation addressed the impact of the integrated palliative care program and the education curricula on care for patients and caregivers. Over 220 patient and caregiver participants contributed to the health outcome evaluation by completing bi-weekly surveys inquiring about patient quality of life and caregiver well-being and caregiver burden. Patients (n=57) and caregivers (n=53) also provided information about satisfaction with care, caregiver needs, available resources, and barriers to care. In addition, one to one interviews were conducted with 39 patients and caregivers to elicit information around the impact of care in the home.

Health care provider focus groups were conducted to determine the effectiveness of the education for changing palliative care providers' knowledge and attitudes concerning end-of-life care and to determine the changes in the delivery of home palliative care following implementation of the integrated model.

Key Findings

1. Seventy-six per cent of clients surveyed indicated that their preferred place to spend their last days was at home. However, there remains a majority who die in hospital and who need to access hospital often through emergency rooms to address their palliative care needs.
2. Individuals 65 years and over and individuals dying from cancer did not access palliative care services in proportion to the respective rate of mortality in the region.
3. A major success was the overall satisfaction clients had with their care. They indicated that the symptoms that had the greatest impact on reducing quality of life are poor appetite, problems with breathing, pain, sleeplessness, fatigue, inability to manage the household, problems with future planning, lack of mobility and problems with decision making.
4. Caregivers indicated a high degree of satisfaction with the care their loved one was receiving. They rated highest the need to have questions answered honestly, to be assured that the best possible care is being provided, to know what treatment the patient is receiving, to feel that the professional care, and to know what symptoms to expect. Unmet needs rated the highest amongst caregivers were information about symptoms and to feel there is hope.
   In addition, correlation analysis indicated that as the client's quality of life decreases, caregiver burden increases.
5. Financial burdens experienced by some participants are caregiver's loss of income, costs of medication, equipment and supplies.
6. The education curriculum was identified as a fundamental component to the development of the integrated palliative care program. Funding allowed for maximum participation.
7. Early successes in the development of the integrated palliative care program were the creation of a common set of palliative care standard, a standardized palliative assessment tool, the palliative care home chart, a standardized bereavement care plan and a single access. In addition, the palliative care consult/resource teams and weekly interdisciplinary palliative care rounds were identified as having a positive impact in the planning and coordination of the complex care needs of clients and families.
8. Significant gaps in service delivery were the lack of 24-hour access; lack of funding for respite and nursing services; lack of funding for palliative care resource/consult teams; lack of appropriate funding for family physicians for palliative home visits; and lack of an integrated information system.

Recommendation #1

Palliative care be identified as a core essential service with home identified as the preferred setting. Service elements will include:

- A coordinated and integrated network of services accessible 24 hours/day.
- Pain and symptom management, psychosocial and spiritual support, counseling for patient and family, family relief/respite and bereavement care.
- An interdisciplinary team of service providers that includes physicians, nurses, home support workers, personal care workers, volunteers, social workers, pastoral care workers, care coordinators, physiotherapists, occupational therapists, respiratory therapists, dieticians and other allied health professionals as needed.
- A palliative care consult/resource team with expertise in pain and symptom management and advanced care planning.
- A leadership structure responsible for program planning, administration and accountability within an integrated framework.

Recommendation #2

Funding of an integrated palliative care program should include planning, development, service delivery, education, evaluation and program support. Specifically, funding would include:

- A program development, education, and evaluation strategy directed by a program coordinator/manager.
- 24-hour access to home care services that can address pain and symptom issues, respite and emotional crisis in the home for palliative patients and families.
- Palliative home care medications from a specified home care formulary.
- Appropriate reimbursement for family physicians providing palliative home care.
- Equipment necessary to promote comfort in the patient's home.
- Palliative care resource/consult teams including physician, nurse, pharmacist and social worker.
- Coordination of volunteer services.
- Coordination of bereavement services.
- An integrated information system for assessment, care planning and evaluation.

Recommendation #3

A comprehensive education strategy addressing the learning needs of resource/consult teams, front-line staff, family physicians, volunteers and the public be an essential element of an integrated palliative care program across all care settings. Specifically, an education strategy would include:

- The funding to coordinate and implement an education strategy.
- The funding for palliative care resource team members including family physicians, to perform an educator role in their region.
- A provincial infrastructure for education to support the development and continuing education needs of the palliative care resource/consult team.
- The funding of a public awareness campaign to educate the public on palliative care philosophy and available services.

Recommendation #4

Palliative care residents living in a long-term care facility be considered as living in their home and have access to the full range of services within the integrated palliative care program. Specifically:

- Appropriate legislation and policy should support a dignified death.
- Palliative care resource/consult teams and long-term care agencies define the linkages with respect to care of the palliative care resident.

Recommendation #5

Regional palliative care programs strengthen linkages with tertiary centres and specialty populations to further expand on the integrated model. Specifically:

- Palliative care programs and regional cancer centres improve accessibility for cancer clients to palliative care.
- Palliative care programs and pediatric centres identify specific palliative care needs for the pediatric client in rural communities.
- Regional and provincial palliative care programs develop linkages to address complex pain and symptom issues, resource/consult team development and research.
- Palliative care programs explore linkages with diagnostic groups such as HIV, neuromuscular, respiratory and cardiovascular diseases.

Recommendation #6

Income assistance and job security be provided to family members choosing to care for a palliative patient at home.

Recommendation #7

A national evaluation strategy be developed that would incorporate research principles and an integrated system for data collection. Specifically, an evaluation component would include:

- Program data collection to help address current palliative care issues and allow for the integration of additional data collection for research purposes.
- A committee to develop guidelines and review applications for outside researchers to conduct research through the palliative program and to ensure that such research is conducted in an ethical manner that respects palliative patients and their families.
- Provincial or national guidelines be developed around standard information to be collected by all palliative care programs to allow comparison across programs.
- The establishment of a provincial, regional and/or national palliative care research centre.

This project has shown that the preferred setting identified by individuals is their home and therefore the focus of program development needs to target home care. In addition, the project provides a template for the development of an integrated service delivery model that builds and strengthens existing resources and recommends provincial and federal governments move to collaboratively fund a strategy that will support end-of-life care for Canadians.

INTRODUCTION

The demand for effective end-of-life care is a challenge facing the Canadian health system, in large part due to the growth of our aging population. In addition, the shift in attitudes towards end-of-life care and the economic realities of hospital care have led to a greater demand for palliative care services in the home.

Most recently, the Senate Subcommittee June 2000 report, *Quality End-Of-Life Care: The Right of Every Canadian* identifies that quality end-of-life care should include:

- Service delivery by interdisciplinary teams
- Access to services in the most appropriate location
- Availability of services when needed, whether for a few hours or around the clock
- Availability of services before death is imminent
- Services for a broad-based clientele both with respect to cultural background and type of illness
- Awareness and skill in pain and symptom management
- Support for caregivers and family members

The challenges of providing effective home palliative care are most notable in rural areas. Compared to urban areas, rural areas tend to have fewer specialists and less access to health care resources. The time to travel the distances to homes to provide care compounds the already high time demands palliative patients often require. Furthermore, the delivery of palliative care tends to require an interdisciplinary team approach and working over long distances presents unique challenges for teamwork and communication.

Previous focus group work conducted around palliative care in rural communities identified that while there are challenges, there are also committed health care resources in rural communities and it is important to build and strengthen what already exists (MacLean, '99).

In response to the challenges of providing palliative care in rural areas the Rural Palliative Home Care Project (RPHCP), a Federal Health Transition Fund project, was an interprovincial initiative with the mandate of developing, implementing and evaluating a model to improve the delivery of palliative care to persons living at home in rural areas. The RPHCP had three demonstration sites, Northern Health Region, Nova Scotia, and East Prince and Southern Kings Health Regions, Prince Edward Island. These sites are rural in nature and characterized by a low population density with the majority of the population clustered in towns and villages. Palliative care services available to these sites prior to the implementation of the new model varied as evident in Table 1.

In addition, the Western Health Region, Nova Scotia participated as a comparison site.

Specific goals of the project were:

1) To increase accessibility to palliative care in rural communities.
2) To increase support to health care providers and facilitate their increased involvement.
3) To develop, implement and evaluate an overall education curriculum.
4) To define the barriers to receiving palliative care in rural communities.

Regional Planning

Program planning was regionally based considering that the three demonstration sites differed in size and resources. It was essential that broad representation from interdisciplinary and interagency stakeholders have a leading role in the development of a regionally integrated palliative care program considering that the principles of integration include coordination, communication and collaboration. In excess of sixty front-line staff, physicians and administration were organized into working groups around service delivery, education, evaluation and, as well, into regional advisory committees.

Early in the planning the project adopted the following assumptions:

1. The development of the model would be in the context of integration.

An integrated service delivery system involves a collaborative network of agencies and service disciplines. Essential features include coordination, continuity, communication, leadership and accountability.

2. The integrated program would include the following core elements:

- Palliative care services that include pain and symptom management; psychosocial and spiritual care; counseling for patients and family; and support services for patients and family at home.
- Palliative care teams that consist of an interdisciplinary team of service providers that may include physicians, nurses, home support workers, personal care workers, volunteers, social workers, physiotherapists, occupational therapists, respiratory therapists, dieticians, pastoral care workers, care coordinators and other allied health professionals as needed.
- A palliative care consult/resource team with expertise in pain and symptom management and advanced care planning.
- Coordinated services that facilitate easy entry into the program, enable movement across the care settings, and eliminate or minimize duplication.
- A leadership structure that is responsible for program planning, administration and accountability.

3. The preferred care setting is the home with acute care and long-term care integrated in the model.

It cannot be understated the tremendous amount of time invested by front line and administrative staff in opting for an integrative process. However, ultimately, this collaborative approach to development was viewed as pivotal to sustainability and future program development.

Table 1: Palliative Care Services Available in Northern Health Region, Nova Scotia and East Prince and Southern Kings Health Regions, Prince Edward Island Prior to Implementation.

	Northern Region, NS	East Prince (EPH) and Southern Kings (SK), PEI
Population	155,834	34,000(EPH) 14,000(SK)
Area (km^2)	12,571	1,202(EPH) 1,114(SK)
Access to home care	7-days/week, 0830 to 1630	5 days/week, 0830 to 1630
Home nursing availability	- no shift nursing - 24 hour availability for preauthorized patients	- no shift nursing - 5 days/week, weekend and evening visits as prescheduled
24-hour respite	no	no
Medication coverage	provincial senior's pharmacare	provincial senior's pharmacare
Palliative care nurse consultation	3.1 full time equivalents in high dense area	no
Palliative care physician consultation	limited, no reimbursement	no
Palliative care volunteers	limited to high dense areas	well developed
Bereavement services	phone follow-up and support groups, but fragmented	volunteer support and a support group(EPH)
Available palliative care data for 1997-98	- 285 referrals - 275 deaths - 58 home deaths	no program in place

PROJECT EVALUATION FRAMEWORK

Evaluation working groups were developed to review the evaluation framework of the project and consider the appropriate processes necessary for implementation. In addition, a training program was developed to assist staff in the recruitment process.

The evaluation for the Rural Palliative Home Care Project included three main components: a needs assessment, process evaluation, and outcome evaluation. It was intended to use a pre-post quasi-experimental design for all elements of the outcome evaluation as well as some elements of the process evaluation. With this in mind, data was collected from the demonstration and comparison sites approximately five months before and seven months after implementation of the integrated service delivery model. However, the number of participants in the study was too small to allow for meaningful pre-post comparisons.

A large majority of the population in the health regions involved in the RPHCP is Caucasian with English as their first language. Within the project sites other cultural groups exist who may have different palliative care needs. To assess this possibility and better understand the provision of palliative care to minority groups, focus groups were conducted with bereaved family members of First Nations and with palliative care providers in a French speaking area.

Ethical Approval and Informed Consent

Ethical approval for all aspects of the evaluation was received from the Research Ethics Committee of the Faculty of Medicine at Dalhousie University and Ethics Committee of the Medical Society of Prince Edward Island. Informed consent was obtained from participants for every phase of the project including data collection through surveys, focus groups and interviews.

Process Evaluation

The goals of the process evaluation were to determine the effectiveness of the education workshops for changing palliative care providers' knowledge and attitudes concerning end-of-life care and to determine changes in the delivery of home palliative care following implementation of the integrated service delivery model. Palliative care team focus groups and family physician focus groups were conducted to meet this goal.

Outcome Evaluation

The ultimate goal of the project was to improve palliative care for patients living at home and their families. Both quantitative and qualitative methods were used to determine whether health outcomes improved after the implementation of the education workshops and integrated service delivery model. All palliative patients living at home who were identified as meeting eligibility criteria were asked to participate in the evaluation component of the project. In addition, their primary informal caregiver (usually a family member) was also asked to participate. The patient and caregiver completed biweekly surveys, a one-time satisfaction with care survey, and a subsample completed face-to-face interviews.

Table 2: Instruments Used in Assessing Health Outcomes and Satisfaction with Care

Completed by Patient	Completed by Caregiver	When Completed
32-item McMaster Quality of Life Scale	Caregiver Role and Well-Being Survey plus Help and Support Survey	Biweekly (surveys completed at the same time by patient and caregiver)
Satisfaction with Care Scale (modified FAMCARE) plus Satisfaction with Pain Management	Caregiver Needs (Family Inventory of Needs) plus Satisfaction with Care (FAMCARE) plus Resources and Barriers to Care	Approximately four weeks after entering the study (surveys completed at the same time by patient and caregiver)
Face-to-Face Home Interviews	Questions related to patients' and caregivers' palliative care needs and health care outcomes, with an emphasis on perceived delivery of care	Completed by a subsample of patients and caregivers (interviews completed together by both patients and caregivers when possible)
Face-to-Face Hospital Interviews	Questions related to the transition from home to hospital	Completed by patients and/or caregivers upon transfer for an overnight stay at hospital (interviews conducted in PEI only)

Provision of Palliative Care in Long-Term Care Settings

To better understand the palliative needs and support of both patients and staff of long-term care facilities, staff, clients, and clients' families completed surveys. Clients who were able were asked to complete the McMaster Quality of Life Scale (MQLS) every two weeks and a family member was asked to complete the Family Inventory of Needs (FIN) and the FAMCARE scale one time only. In addition, at the same time the MQLS was completed, all relevant staff for that client completed a Caregiver Survey that assessed their role as a palliative caregiver for that particular client as well as the perceived effects of providing care on their own well-being.

Client/ Caregiver Characteristics

Screening and Recruitment

Front-line workers were asked to complete a short Caregiver and Client Screening Survey for any client they thought was palliative and who was living at home. Client Screening Surveys were supposed to be completed for all palliative clients living at home, regardless of whether or not they were eligible to participate in the study. A total of 502 clients were screened for the study, 286 from the Northern Health Region, Nova Scotia, 59 from East Prince and Southern Health Regions, Prince Edward Island, and 157 from the Western Health Region (comparison site). Of the 502 screened clients, 155 (30.9%) met eligibility criteria and were asked by a front-line worker if they would allow a project coordinator to come to their home to explain the study in more detail. Caregivers were also asked if they wanted to hear more about the study. If agreeable these potential participants then received a home visit to explain the study. Clients and caregivers agreeing to participate completed a written consent, a demographic interview, as well as the first of the bi-weekly McMaster Quality of Life Scale and Caregiver Survey.

As a result of the screening and recruitment process, 81 client/caregiver dyads and an additional 30 clients and 32 caregivers participated in the evaluation. Thus information was obtained from 111 clients and 113 caregivers.

Potential Sample Bias

At the beginning of the evaluation, based on mortality statistics for cancer deaths, it was estimated that there should be approximately 1100 clients screened for the study. In total, 149 client/caregiver dyads or individual clients or caregivers participated in the study. Thus, only approximately 13.5% of palliative clients are represented in this study. Results from a Screening and Recruitment Feedback Survey administered to front-line workers after the evaluation phase was complete indicated that the two main reasons for not screening and recruiting clients were front-line workers' perceiving many clients to be identified as palliative too late to be recruited into the study and that the person doing the screening judged the client and family as too stressed and burdened to participate in the study. With this in mind, the observations made by one front-line worker on the Screening and Recruitment Feedback Survey that this study *likely underestimates the needs and overestimates the coping ability of palliative care clients and families* should be well heeded. It should be emphasized that any results from the evaluation be interpreted keeping in mind the limitations of the sample, both in terms of its size and representativeness.

The goals of the needs assessment were:

- To inform the demonstration sites of the development needs in education and service delivery in the planning of an integrated palliative care program.
- To obtain a comprehensive understanding of the needs of palliative patients and families living at home in rural areas as well as the needs of the health care providers delivering this care.

The components of the needs assessment included focus groups with palliative health care providers, key informant interviews and combinations of family physician focus groups and interviews.

Health Care Provider Focus Groups

Focus groups were conducted prior to the development and implementation of the integrated model. Two focus groups were conducted in the Nova Scotia demonstration site and one each in the Prince Edward Island demonstration sites. Each focus group consisted of 8-11 participants and typically represented members from clergy, home care, long-term care, nursing, pharmacy, social work, volunteers, and a palliative care consumer (one focus group only). Although a physician attended one of the focus groups, scheduling difficulties precluded their participation in the others. However, the project was informed by separately conducted focus groups of family physicians.

The main topics included the availability of palliative care resources, how palliative care is delivered,,, barriers to providing effective palliative care, palliative care educational needs and the preferred format for receiving palliative care education.

Key Informant Interviews

Key informant interviews were conducted with individuals in each demonstration site. Individuals were identified who could best provide an overview of the entire palliative system for that region. One to one interviews were designed primarily to elicit information concerning areas of palliative care that were targeted for change with the introduction of the integrated service delivery model. They included: accessing services, coordination of services, communication among team members, duplication of services, role boundary and role confusion, gaps in the delivery of palliative care, sources of information and knowledge around difficult palliative care issues and system response to an emergency in the middle of the night.

There was considerable overlap between the health care provider focus groups and key informant interviews concerning needs in the delivery of palliative care. Presented together in Table 3, they identified gaps in accessibility, care of patients and caregivers, human resources, coordination, communication and integration.

Accessibility

- Availability of hospital bed for direct admission
- Better integration for system entry (i.e., single entry)
- 24-hour access
- An identified barrier is long distances to clients' homes

Issues Around Care of Patients and Caregivers

- More spiritual support
- More bereavement care
- Costs of medications and supplies to clients are a barrier
- Better education for clients and families around physical changes that can be expected, service options, and how to do home procedures (e.g., bed baths, transfers, lifts, changing a bed with a bed-ridden client)

Human Resource Issues

- Physicians to adopt palliative care philosophy and develop greater palliative care expertise
- Remuneration to doctors to facilitate palliative care involvement
- More volunteers and reimbursement for out of pocket expenses
- More support for health care providers, particularly dealing around their own grief and bereavement around the loss of a client
- Local palliative care resource teams
- Palliative care training of front-line workers, specifically pain and symptom management, emotional support and communication with families

Coordination, Communication, Integration

- Improved discharge planning
- Better integration and communication among agencies
- Reduce amount of overlap of assessments among agencies
- Services to be consistent across entire region
- System to be less restrictive and bureaucratic
- Less crisis orientation to care and more time to deal with psychological and emotional aspects of palliative care

Family Physician Focus Groups

Prior to the initiation of the Rural Palliative Home Care Project, preliminary inquiry had been conducted among family physicians in Nova Scotia regarding the provision of palliative care. In 1998, six focus groups were held representing family physicians in a variety of practice settings. At these focus groups, physicians were asked to reflect on changes in the health care system in Nova Scotia and to describe what

has worked well and what could be done differently to enhance care for those at the end of life. Additional areas of inquiry centered on the needs and availability of resources, how interdisciplinary care works in their communities and about perceived knowledge gaps they might have in providing end-of-life care. Two additional family physician focus groups conducted in the project demonstration sites of Prince Edward Island identified similar issues.

Resources

- Timely access to adequate home care
- Access to hospital admission when needed
- Access to drugs and equipment
- Support of the interdisciplinary health care team
- Access to special expertise in palliative care

Family Support

- Family availability to patients
- Family in agreement with treatment goals
- Family members must have the physical and emotional personal resources to cope

Time and Money

- Adequacy of physician time to spend with patients and families
- Adequacy of physician remuneration for this time in varying settings (office, home, hospital)

Symptom Control

- Need to ensure minimal pain and other symptoms
- Methods to overcome patient and family barriers to adequate symptom control
- Accessibility of focused literature resources

To determine referral and mortality data, the new palliative care programs in the three demonstration sites provided the following administrative data:

Number of referrals
Hospital admissions
Breakdown by diagnosis
Equipment needs
Emergency room visits and reasons
Nursing and home support requirements
Reasons for referral
Age breakdown
Survival time
Days at home and days in hospital
Place of death

THE EDUCATION CURRICULA

To meet the project goal of developing and evaluating education curricula and to support the roles and responsibilities outlined in the new palliative care programs, two education working groups were formed, one in PEI and one in Nova Scotia. These groups had multidisciplinary representation and collaborated with the education consultants in all phases of the educational initiative.

The educational initiative for the project consisted of three parts:

- Multidisciplinary Front-Line Education
- Resource Team Education
- Faculty Development

The strategy used for the front-line education included the involvement of education working groups, a comprehensive needs assessment, the development and delivery of a three-day curriculum (19.5 hours of content) and a comprehensive evaluation process. The following is an outline of the sessions delivered over the three-day period.

	Topic	**Time**
Session 1:	Principles and Practices of Palliative Care	1.5 hours
Session 2:	Dealing with Death Personally and Culturally	1 hour
Session 3:	Interdisciplinary Team	1 hour
Session 4A:	Introduction to Pain Management, (RN/LPN/Pharmacy)	3 hours
Session 4B:	Understanding the Dying Person's Experience & Pain Management (Personal Care Worker/Pastoral Care/Social Worker)	3 hours
Session 5A:	Symptom Management (RN/LPN/ Pharmacy)	3 hours
Session 5B:	Personal Care and Symptom Management (Personal Care Worker, Pastoral Care, Social Work)	3 hours
Session 6:	Communications	2 hours
Session 7:	Spiritual Care	1.5 hours
Session 8:	Family Centered Care	2 hours
Session 9:	The Dying Process	1 hour
Session 10:	Grief and Bereavement	2 hours
Session 11:	Self-Care and Closure	1.5 hours

The curriculum was delivered in five sites (Amherst, Pictou and Truro in Nova Scotia, Montague and Summerside in Prince Edward Island) to 226 multidisciplinary front-line health care providers, clergy and volunteers. Attendance for all three days was 87%, while 5% attended two days only and 8% attended only one day due to workplace staffing shortages and illness. The initial day was delivered one to two months ahead of the remaining two days. This was necessary in order to provide for maximum participation in the regions (met staffing needs) and allowed time for the knowledge gained from the first session to be assimilated and put into practice. The faculty consisted of local presenters and palliative care specialists. The content was presented using lectures, small and large group discussion, interactive exercises and role-play. A case-based approach was used as often as possible in order to relate theory to real situations.

The evaluation consisted of three parts including a survey measuring satisfaction with curriculum presentation, a written pre, post and three-month post-retention test and a questionnaire regarding the impact of the education on clinical practice. Participants across all sites indicated high satisfaction with the presentations as well as the set-up and structure of the education sessions. Results of the pre and post tests indicated an overall significant increase in palliative care knowledge for participants with both a clinical and non-clinical background. It was shown in the follow up results that both the clinical and non-clinical groups retained knowledge over a three-month period. On the questionnaire regarding changes to clinical practice, respondents indicated the greatest perceived changes were related to an increase in general knowledge of the principles and practices of palliative care, pain and symptom management, family centred care and communication. Indicated as well was an increased comfort in their role of palliative care service provider.

The strategy used for the resource team education included the involvement of education working groups, a comprehensive needs assessment, the development and delivery of a nine-day curriculum and a comprehensive evaluation process.

Twenty-five individuals (12 nurses, six physicians, four pharmacists and three social workers) made up the five interdisciplinary resource teams that included, at a minimum, a physician and nurses, and at a maximum a physician, nurses, a social worker and a pharmacist.

The curriculum developed by a multidisciplinary palliative care team from the Queen Elizabeth II Health Sciences Centre and the IWK/Grace Health Center, was delivered over three months in two and three-day segments to allow for retention and application between sessions. All but one session was presented to the entire interdisciplinary team. One discipline specific session allowed for further attention to discipline specific needs. Each regional team worked together as much as possible in order to facilitate team building. The content was presented using lectures, small and large group discussion, interactive exercises and role-play. A case-based approach was frequently used in order to relate theory to clinical situations. Resource team members were encouraged to submit cases for discussion. Faculty consisted of multidisciplinary palliative care specialists from Halifax and Sydney as well as content experts in the subject matter being delivered.

The following is an outline of the curriculum sessions for each of the three weekends.

Weekend One "Education for Physicians in End-of-Life Care" Curriculum (EPEC)

The first weekend used a new curriculum called Education for Physicians on End of Life Care (EPEC 1999), developed by palliative care experts for the American Medical Association.

	Topic
Opening Plenary:	Canadian Issues in Palliative Care
Module One:	Advance Care Planning
Module Two:	Communicating Bad News
Module Three:	Whole Patient Assessment
Module Four:	Pain Management
Module Five:	Physician-Assisted Suicide
Module Six:	Depression, Anxiety, Delirium
Module Seven:	Goals of Care
Module Eight:	Sudden Illness

Module Nine:	Medical Futility
Module Ten:	Common Physical Symptoms
Module Eleven:	Withholding, Withdrawing Therapy
Module Twelve:	Last Hours of Living
Closing Plenary:	Provincial Initiatives (Nova Scotia and Prince Edward Island)

Weekend 2

	Topic
Session One:	Clinician-Patient Communication to Enhance Outcomes (The Bayer Institute)
Session Two:	Family Centered Care
Session Three:	Narratives in Everyday Practice
Session Four:	True Colors: A Team Building Exercise
Session Five (A):	Pain Management (MD, RN & Pharmacy)
Session Five (B):	Social Work Issues (Social Workers)
Session Six:	The Child as a Family Member
Session Seven:	Dancing Inside: An Alzheimer Story

Weekends two and three were developed for the participants based on the results of their needs assessments.

Weekend 3

	Topic
Session One:	Death in the Home
Session Two:	Cardio-Respiratory End-of-Life Care
Session Three:	Discipline Specific Session - Nursing, Pharmacy, Physicians, Social Worker
Session Four:	Group Casework in Teams
Session Five:	End-of-Life Spirituality
Session Six:	Grief and Bereavement
Session Seven (A):	Pain Management (MD, RN & Pharmacy)
Session Seven (B):	Bereavement Support & Group Work (Social Workers)
Session Eight:	Team Conflict
Session Nine:	The Child as a Patient
Session Ten:	Legal Issues

The evaluation consisted of three parts including a survey measuring satisfaction with curriculum presentation, a written pre, post and retention test and a post intervention focus group regarding the impact of the education on clinical practice. Participants indicated high satisfaction with presentations as well as curriculum content and workshop set-up. Surveys showed a large, significant increase in knowledge from pre to post tests with a modest increase on the retention test completed five months after the intervention. This supports the point that education with immediate practice application in the integrated model allows for knowledge retention. Health care provider focus groups reported increased confidence, appreciation of team approaches and regional perceptions of improved care as a result of the resource team roles.

In addition to the classroom curriculum a five-day clinical practicum was offered to those physicians and nurses who were new to the role of palliative care resource team member (a total of four physicians and nine nurses). All nurses and two physicians spent time with the palliative care team at the QEII. The remaining two physicians spent time with the palliative care service at the Cape Breton Healthcare Complex. The clinical experience was based upon the individual needs assessment and objectives of the participants.

Participants were asked to complete a post clinical satisfaction survey. Overall, nurses and physicians viewed this as a very positive learning experience allowing them to see the theoretical knowledge they gained put into practice.

It was recognized by the education consultants that development and delivery of the education curricula for both the front-line and resource teams was going to require the assistance of many individuals. The need for training to prepare for the educator role was identified by potential faculty members. In response to this identified need, and in an effort to promote sustainable education strategies, faculty development became one of the education initiatives of this project.

There were two phases to faculty development. Phase one was delivered prior to any education initiative in the regions with the goal to prepare faculty to deliver the project's education initiatives. Phase two, the last initiative delivered, was designed to prepare the newly formed resource teams as ongoing educators in palliative care.

Phase 1

It was an objective of the education working groups to identify individuals in their respective regions and provinces who were currently providing palliative care education. Many of these individuals from across Nova Scotia and PEI were contacted to participate in a faculty development workshop. Participation was multidisciplinary, although limited to one person from PEI due to scheduling conflicts. Two consultants were contracted to develop and deliver the workshop.

The content presented was based on a needs assessment completed prior to beginning the workshop. Topics included:

- Systematic education program planning
- Identification of needs of adult learner and strategies to meet the needs
- Educational methods
- Strategies to become a reflective practitioner
- Resources to assist the educator

Phase 2

The newly formed resource teams recognized that as they became known in their regions as "experts" they would be asked to deliver education sessions on palliative care.

In order to provide team members with theoretical background to the role as educator, a one-day *Adult Education: Training Trainers Workshop* was developed. Topics presented included:

- Principles of Adult Education
- Teaching and Learning Styles
- Development, Delivery and Evaluation of Educational Programs
- Dealing With Difficult Participants
- Handling the Unexpected

Specific objectives for the session included:

1. Identify how you learn.
2. Describe different teaching styles.
3. Identify ways personal style can impact the training experience.
4. Identify the principles of adult education.
5. Identify characteristics of adult learners.
6. Identify factors influencing learning.
7. Identify the steps to follow in developing an educational program.
8. Identify trainer skills.
9. Become aware of how to handle difficult participants.
10. Identify specific tips that may help in facilitating an educational program.
11. Identify active training methods and how and when to use each.
12. Identify audiovisual aids that may be used and tips for how to use each.
13. Become familiar with the various room arrangements used and when to use each.
14. Become familiar with methods used to evaluate the educational experience.

The project's education consultants using lectures, small and large group discussion, interactive exercises, role-play and a team assignment presented the content. To provide experience in planning a program each team completed an exercise in planning a palliative care education session. Teams had the opportunity to present their plan to the larger group for comments, suggestions and questions.

It is noteworthy that since coming together, these new teams had either already delivered palliative care education or had sessions planned.

Participants completed a satisfaction survey following the session and reported high satisfaction with workshop presentation, content and set-up.

DEVELOPMENT AND IMPLEMENTATION OF THE INTEGRATED PALLIATIVE CARE PROGRAMS

Service delivery working groups were created in the three demonstration sites to construct a conceptual model and an implementation strategy towards the development of an integrated palliative care program in their region.

The Development of Standards and a Service Delivery Framework

The development of program standards by the regions was guided by the *Canadian Palliative Care Association Document "Palliative Care: Towards a Consensus in Standardized Principles of Practice."* The consensus for a common set of standards was undisputed. However, the challenges of incorporating other interagency standards and the fear of creating standards that could not be met were barriers that working groups did overcome. Regions identified the importance of integration for program success and incorporated this principle in their program purpose.

> *The Integrated Palliative Care Program is a network of services delivered by an interdisciplinary team, for individuals and families who are living with or dying from a progressive life threatening illness or who are bereaved. The integrated model provides comprehensive and coordinated care addressing the physical, psychological, social, and spiritual needs of the individuals. (Program Purpose)*

Team members and agencies now have a common set of standards that provide the definition, purpose, guiding principles, goals and objectives, and program outcomes that form the foundation of their programs.

> *"Palliative care is the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with or dying from progressive life threatening illness, or who are bereaved." (CPCA, 1997).*

Working groups considered how palliative care patients and families' needs were currently met. Members shared their various experiences and perspectives as to how patients moved through the existing system using flow diagrams. This proved to be an effective way for committee members to start developing a common understanding of systems barriers. Specifically, members identified lack of an easy access system, too many assessments, lack of coordination and continuity, inconsistent access to palliative care resource/consult teams, and communication challenges amongst team members, especially across care settings.

The logic model was used as a tool to develop a new systems framework for an integrated program. This systematic representation of a program illustrates its components, outcomes and overall effects. The service delivery working group developed the logic model outlined in Table 5 and identified six components needed to establish an integrated palliative care program: 1) referral, 2) assessment, 3) coordination, 4) care delivery, 5) consultation, and 6) community resources. Although proving to be an effective tool, this was a labor-intensive process while committee members outlined the activities, objectives, and outcomes of each component often spending considerable time coming to a consensus.

Table 5: Rural Palliative Home Care Project: Integrated Palliative Care Logic Model

	Referral	Assessment	Coordination	Care Delivery	Consultation	Community Resources
Activities	• Quick response • Baseline data • Intake • Single access	• Assessment strategy • Common palliative assessment tool(s)	• Facilitate development implementation and evaluation of a care plan • Facilitate movement across care settings • Weekly rounds	*Physical* • Pain & symptom management • Personal care *Psycho-social* • Psychological & social support • Respite *Spiritual* *Bereavement Care*	• Complex pain & symptom management • Advanced care planning • Counseling • Education	• Emotional support • Leisure activities • Transportation • Companionship • Financial and in-kind contributions
Elements	• Pt/family • Referral sources (health care team & community) • HC coordinator • Nursing & home support • Palliative care nurse	• Pt/family • Palliative care consultants • Family Physician • HC Coordinator • Referral Source • Health care providers	• Pt/family • HC Coordinator • PC Nurse • Health Care Providers	• Pt/family • Nursing and home support • Home care, long-term care, hospital • Family Physician • Interdisciplinary team, clergy, volunteer • Community service	• Pt/family • Family physician • Home care coordinator • Health care providers • Palliative care consult team • Specialists	• PC volunteer • PC volunteer coordinator • Community volunteers • Hospice Society • Non-government organizations • Veteran's Affairs Canada (VAC)
Outcomes	• Referrals from health care providers and community • Timely response	• Pt/family needs are identified in the palliative care chart • Minimal duplication • Baseline data	• Case manager identified • Care plan development with pt/family input • Options discussed • Care plan communicated	• Pt's symptoms are controlled • Pt/family are satisfied that their needs for support are met and in the most appropriate setting • ↓Admissions to ER	• Complex P&S are controlled • Evidence of advanced planning • Pt/family grief related needs are met • Adverse effects controlled • Education provided	• Standardized volunteer PC program • Community resources & volunteers are matched with pt/family needs
Objectives	• Provide easy access • Provide essential services in a timely fashion	• Assist pt/family identify their needs and or expectations • Conduct one palliative care assessment that will travel with the pt. • Limit duplication	• Coordinate a continuous care plan • Involve pt/family in the planning • Limit duplication	• Provide palliative care to pt/family where and when it is needed • Access palliative care consultants when needed	• Accessible to team • Provide advice and leadership on pain/symptom management, psychological, social & spiritual issues • Provide PC education to health care providers and public	• Partner with community resources • Facilitate ongoing public education
Effects	• Access to palliative services is evident & timely. • Services are provided in an appropriate setting. • Continuity of service is evident. • A coordinated system for assessment, care planning and service provision is provided. • Care meets the needs and expectations of patients/families.			• Total pain and other symptoms are alleviated to the greatest extent possible. • The patient with life threatening illness is assisted to live and die in comfort and dignity. • Bereavement follow-up and support is available.		

Working groups created an implementation strategy to operationalize their model. Specifically, they developed functional components which in turn generated defined roles and responsibilities, a single entry, common assessment tools, a case management function, a home chart, weekly rounds, a bereavement care plan, palliative care resource/consult teams and mechanisms for program data collection. In addition, an information systems needs assessment was conducted to identify the processes required to support an integrated model.

Resources mobilized to deliver the programs varied among the demonstration sites based on human and fiscal resources available at the time, as seen in Table 6.

Challenges occurred during implementation in all three regions. The new assessment tools, home chart, and program functions, along with the education commitments, led to heavy workload issues for team members. In addition, while the development of new roles and relationships is an evolving process it frequently created confusion and uncertainty. This required frequent facilitated discussions with team members and developmental flexibility to change what was not effective. Although viewed as successful in the end, the amount of change experienced during a compressed timeline was reported as stressful.

Functional Components of the Integrated Service Delivery Model

Preliminary focus groups indicated that the lack of formal and integrated palliative care programs created confusion and inconsistencies regarding access to palliative care. Working groups considered existing referral points in the region that could be integrated into a new palliative care program to avoid duplication. All demonstration sites identified their home care agencies as the logical point of entry. Currently it is available seven days per week (five days per week in PEI) during normal working hours and staffed by professional care coordinators. The new programs introduced this regional entry point as an addition to traditional means of access (corridor consults, calling individual providers). The referral duties include intake, screening for quick response, collecting baseline data, providing information to the public, and directing the referral to the appropriate care coordinator and palliative care nurse. The regional number is published on the program brochures, which is available throughout and outside the regions.

A common palliative care assessment tool, which is conducted with the client/family by health care professionals, has been piloted successfully.

It is suggested that this assessment be completed at a pace that is appropriate for the individual client and family and in collaboration with the primary and consult/resource team. It is designed to determine with the client/family what their needs and expectations are for their care and as well to identify with them such things as their coping mechanisms and supports. The goal is to have the assessment completed within 4-5 visits of intake.

An open box format to the questions, evident on the *"Palliative Care Assessment Tool,"* allows the assessor to record responses in the client/family's own words and to conduct the interview using open-ended questions.

Staff were provided with orientation guidelines to the assessment tool that included recommended leading questions.

Palliative Care Assessment

Client Name _____ Health Number _____

Caregiver Name _____ Relationship _____

1. Description of illness (patient/caregiver informed, hopes for the future, patient need for more info)

2. Communication: (participates in decision making, able to express concerns, support system)

3. Coping: (identification of stressors and coping mechanisms, support system)

4. Financial Concerns: (income loss, costs of equipment and medication)

_____

_____

_____

Integrated Palliative Care Program: PC Assessment: June, 2000

5 Spiritual and Cultural Values (impact on care; support system)

6. Activities of Daily Living (I = independent, D = dependent, AD = assist devices, A = assist from others)

_____ bathing (tub/shower)	_____ toileting	_____ feeding	_____ medication management
_____ food preparation	_____ stair climbing	_____ transportation	_____ treatments
_____ housekeeping	_____ dressing/grooming	_____ laundry	_____ finance management
_____ walking	_____ transfers		

Home care support identified as needed: ☐ yes ☐ no

7. Advanced care planning: _____

_____

8. Identified Needs and Expectations: _____

_____

9. Additional Comments and Referrals: _____

_____

10. Can we contact any of your identified support people? (Name and phone #'s)

Name	Relationship	Phone Number

Signature: _____ Position: _____ Date: _____

Integrated Palliative Care Program: PC Assessment: June, 2000

Palliative Care Home Chart

Further, an integrated palliative home chart was developed. The purpose of the palliative home chart was to improve palliative care assessment, eliminate duplication and improve communication among health care providers around patient/family care. The chart remains in the patient's home and is brought to various care settings such as physician's offices, clinic, hospital and emergency departments. Collaboration and commitment from key stakeholders were instrumental in working through these and other challenges in the chart development. In Nova Scotia a letter of agreement among the Northern Regional Health Board, the Department of Health and Victorian Order of Nurses was developed in order to move to an integrated chart.

Overall, the implementation of the palliative home care chart was a success. Palliative care focus groups reported the palliative assessment tools in the new chart provided a more comprehensive overview of the patient/caregiver needs and expectations. It reduced multiple assessments of clients/caregivers and increased communication and continuity of care amongst team members. Some of the major challenges faced were agreeing on chart content, the amount of paper and compliance by all health care providers to use and complete the chart. However the current concern is the inability of the health care provider to access patient care information when not with the patient. This is seen as critical considering that there is a tremendous amount of office/phone consultation and care planning at rounds. Although there is some documentation duplicated for office reference this is not ideal, as it may not reflect the patient's most recent status. In addition, team members expressed their frustration with the large volume of paper. The 'information systems needs assessment' provides recommendations for an electronic chart to overcome these issues.

3) Coordination

A coordinated, continuous plan of palliative care, which minimizes duplication, is maintained across all care settings from the client's admission, to bereavement support for the family (Program Standard).

Each client/family is assigned a case manager who collaborates with the palliative care consult team and appropriate interdisciplinary team members to coordinate a continuous care plan.

Case management is an evolving function for the team, primarily assigned to the home care coordinators and palliative care consult nurses in the Nova Scotia site and the home care nurses in the PEI sites. Identified as key to ensure continuity across care settings and in the coordination of resources to support the palliative care plan, these team members explored how to consistently identify a case manager for each palliative client. This is a challenging process, demanding time commitment and trust amongst team members.

Palliative Care Rounds

A tool to enhance coordination and communication is weekly rounds.

The palliative care consult/resource team, home care coordinator, hospice/palliative volunteer coordinator, pastoral care advisor, home nursing (supervisor in Northern Region, NS), clinical leaders and discharge planner meet weekly to evaluate patient/family care plans. Additional team members participate on an as needed basis. A care plan tool was developed to assist in the planning.

Teams report that rounds have become an integral part of the program. It eliminated previous practice of chasing people on the phone. In addition members felt a trust develop as they grew to better understand roles and expertise. Ultimately, there was improved planning around patient/family care.

An identified challenge is including primary team members particularly the home care nurse and family physician due to time and human resources. Speakerphone technology has been successfully employed and Telehealth is being explored as another option

4) Care Delivery

Care is directed towards meeting the physical, psychosocial, and spiritual needs of the client and family, in a manner sensitive to their personal, cultural, and religious beliefs, values and practices (Program Standards)

A coordinated team of primary care providers collaborates to meet the physical, spiritual and psychosocial needs of the client/family. The team includes the family physician, care coordinator, and depending on the needs of the family, may include a nurse, home support worker, social worker, pharmacist, pastoral care, palliative care volunteer, dietician, occupational therapist, and physiotherapist. Team coordination and communication is facilitated through weekly palliative rounds.

In the Northern Health Region clients, with a life expectancy of less than three months, and who choose to receive care at home were eligible to receive longer nursing visits and increased hours of home support for family relief. In addition, medications related to the client's palliative care needs and that are listed in the palliative care formulary were covered when a financial need was identified.

Bereavement Care

Bereavement care is a fundamental component of care delivery and was made available to all families/caregivers by volunteers and palliative care social workers as outlined in the 'Bereavement Standard Care Plan'. Volunteer phone follow-up, grief counseling and mental health referral for complicated grief issues are included in the plan.

Bereavement Standard Care Plan

Belief: It is the belief of the Palliative Care Program that grief is an important aspect of the palliative experience. Grief can be addressed through the psychological, social, physical and spiritual realms of well being. It is the hope/goal that the loss, grief, death planning and bereavement support meets the expectations and needs of clients and families to their satisfaction.

Purpose: Interdisciplinary team members will provide support during the grief process to clients/family/caregivers and each other. The team recognizes anticipatory grief as part of the grief process.

GOALS and OBJECTIVES:

To provide information about the grief process.

- Clients and caregivers will be assessed for their need for information about the grief process. Available information includes "Preparing for an Expected Death at Home," and "What Do I Do Now?" Age appropriate information for children is selected on a case by case basis. Team members will assess for literacy and re-assess client/caregivers need for information and support on an ongoing basis.

To be aware of support services for the bereaved.

- Team members will provide bereaved individuals access s to appropriate support services.

To assess and monitor the caregivers coping strategies and support systems.

- An initial assessment will include the impact of the illness on clients, the family and caregivers.
- Deaths will be announced at weekly rounds at which time a sympathy card will be sent and a specific team member will make contact with the bereaved person(s).
- When the bereaved individual agrees to a phone follow-up, a volunteer coordinator will arrange for a trained volunteer to make contact at monthly intervals of 1,2,3,6,12,18, and 24 months. In addition the volunteer will also call on anniversaries, birthdays and all significant holidays and dates for that individual.

To asses impact of the death on the family functions, in terms of financial, emotional, psychological and spiritual well being.

- The initial palliative care assessment will include an assessment of the family dynamics and individual family roles.
- Team members will provide emotional support and education as family members adjust to potential role changes due to loss.

To provide support for caregivers with complicated grief.

- Potential or anticipated complicated grief issues will be referred to the palliative care social worker for follow-up. (i.e., children, multiple losses).
- Volunteers will report any complicated grief issues to the volunteer coordinator and in turn will be forwarded to the palliative care social worker. The social worker will provide an assessment and determine the need for a mental health or other appropriate referral.

To facilitate development of resources as needed.

- Team members will identify and address the gaps in bereavement services/resources, as identified by community, clients and caregivers.
- Team members will facilitate the development of identified resources/services.

Team members are encouraged to recognize and address their own grief issues.

- Team members will be advised of their client's death in a timely manner, to ensure the opportunity to attend funeral services.
- Team members are encouraged to support one another during the grief process.
- Team members are encouraged to identify any related issues that they are experiencing due to unresolved personal/professional loss and seek assistance.
- Team members are encouraged to have individualized care plans to ensure self care, which will include all four realms: physical, social, psychological and spiritual.
- Team members can seek grief support from the palliative care social worker, pastoral care and/or alternative professional individuals, i.e., EAP for support and/or referral.

Memorial services will be held at least annually honoring the memory of the deceased clients on the palliative care program.

5) Consultation

"Without the palliative care experts, I wouldn't be able to provide home based palliative care" (family physician)

Specialized clinical teams with training and expertise in complex pain and symptom management, advanced care planning, and grief counseling are an essential component of the palliative care program. These palliative care consult/resource teams typically included a physician, nurse, pharmacist, and social worker. Their role is to provide clinical support to the primary team, provide program leadership and palliative care education.

In a very short time consultations to all resource team members were taking place. It was noted that being part of a formal team with specialized training brought credibility to these new roles. This was supported by the family physicians who expressed the need for experts as important.

Social work and pharmacy were not included on all palliative care consult teams due to the lack of available fiscal or human resources. Considering the challenges presented to teams in complex family dynamics and in some complex pharmaceutical interventions, the absence of these roles is identified as a gap.

6) Community Resources

Community resources can be a source of both emotional and practical support for the client/ family. Community resources may be formal through palliative care volunteers, hospice societies, non-government organizations, and service clubs or informal through neighbors and local community groups.

For example, all regions depend on the community for equipment. In the Prince Edward Island sites, Home Care and the community collaborate in the coordination of equipment. That is, Home Care stores, maintains, and distributes while the community donates what is needed.

In the Northern Health Region service clubs and volunteer organizations are the main source.

There were three hospice organizations providing support to their communities and to their palliative care programs in varying capacities from supplying equipment, funding patient/caregiver needs, funding of education for staff and training and coordinating volunteers.

Table 6: Palliative Care Service Enhancements in Three Demonstration Sites

Team Members	Northern Health Region, Nova Scotia	East Prince Health Region and Southern Kings Health Region, Prince Edward Island
Palliative care nurses	Increase from 3.1 to 5.2 FTE funded positions on three teams	4 staff as resource nurses for two teams; no dedicated funding
Palliative care physicians	3 physicians for three teams; sessional funding 9 hours/week	2 physicians for 2 teams; no dedicated funding
Palliative care social worker	2 x .5 FTE social workers for two teams; reallocated existing resources	Not available
Palliative care pharmacist	3 pharmacists from existing resources	1 trained for one site from existing resources; no available pharmacist in the second site
Medications	Medication coverage (from a specific palliative care formulary) when a financial burden is identified	No change
Respite	Flexible funding to allow increased hours as needed and 24-hour shift for end-of-life care	No change
Visiting nursing services	Flexible funding to allow for increase frequency in visits and shift nursing for end-of-life care	No change

Roles and Responsibilities

Descriptions of roles and responsibilities were developed in consultation with the team. There may be some regional variances between Prince Edward Island and Nova Scotia. New roles have emerged, but most of the roles outlined in Table 7 previously existed in the system and were enhanced through education and new linkages. The challenges and stress experienced by some staff due to the new roles, new relationships, and a new program implemented in a condensed time frame, needs to be acknowledged. Particularly, the consult/resource team, the home care coordinator and the primary team continue to address role issues as they evolve.

Palliative Care Consult/Resource Team

The palliative consult/resource team is one component of the broader interdisciplinary team responsible for the care of the patient and family. The future success and sustainability of this team will be the interface with the primary team. Consequently, one challenge is making the role distinction between the primary care team and the consult team and recognizing there is a need for balance That is, roles should be flexible and responsive to patient/family needs, at the same time avoiding role confusion and duplication. This issue was a team concern but rarely identified as an issue by patients and caregivers.

Home Care Coordinator

A strengthened role in the palliative care program in the Northern Region, Nova Scotia was that of the home care coordinator. A core group were designated to the palliative care teams and assigned a case grouping of palliative clients. Overall, team members identified that having designated home care

coordinators improved communication and coordination. In fact, there was a growing practice amongst the home care coordinators and palliative care consult nurses to conduct joint visits. However, a few coordinators felt that they preferred a mixed caseload and expressed that home care coordinators, not directly involved with the program, wished to coordinate care for palliative care clients.

Primary Care Team

The primary care team is accountable for the care of palliative care patients and families on the palliative care program. The front-line education prepared nurses, home support, social workers, volunteers, clergy and other allied health staff with the knowledge to provide support to palliative care patients and families in the home. In addition, it prepared them to operate in the new model introduced in the regions. Palliative care consult nurses identified that the increased number of referrals and consultations are an indication of improved communication and clinical coordination between the consult team and the primary team. As previously discussed it remains a challenge to maintain clarity of these roles.

Family Physician

Clients and caregivers report that family physicians provided valuable support to them. As clients and caregivers identified their need for information about their disease processes, symptoms and test results, it is apparent that there is a critical role for their family physician.

However, integrating the family physician into the palliative care team is wrought with challenges due to the necessary time commitments of palliative care, rural geography, cost and competing duties. After hours medical care for clients at home is, for the most part, not available and patients are often instructed to visit the emergency department. The time to drive and meet the needs of a client and family on a home visit is costly for physicians both monetarily as well as for time allocation when they have an office of waiting patients. In addition, rural physicians are at a disadvantage to attend educational workshops on pain and symptom issues due to the competing priorities of other disease processes time and appropriate reimbursement/ income loss. Physicians indicate that they are happy to collaborate, appreciating the skills of the palliative care team members. However, in a time that lacks physician availability, there is a risk of the physician relinquishing primary responsibility to the resource/consult team. This would not be in keeping with the integrated model that identifies the primary team as accountable for care. In order for physicians to meet their responsibility appropriate reimbursement and after hours medical coverage will need to be addressed

Palliative Care Resource Physician

- Provides a palliative care medical assessment for clients referred by their family physician. Supports family physicians in the care of palliative care clients and families
- Provides education to family physicians in the care of palliative care clients and families
- Participates in weekly palliative care rounds
- Provides consultation to palliative care team members
- Participates in the development, implementation, and evaluation of clinical protocols and practice guidelines
- Contributes to the palliative care knowledge of the team

(Note: The palliative care physician provides a consultative role rather than primary care)

Palliative Care Resource/ Consultant Nurse

- Provides palliative leadership to the team
- Provides clinical support to primary nurses in all care settings
- Facilitates palliative care rounds
- Collaborates in the assessment of all palliative care clients and families
- Collaborates in the development of the palliative care plan
- Provides clinical expertise/ case management to clients and families with complex pain and symptom management issues
- Develops nursing strategy with primary nurses for clients and families with complex pain and symptom management issues
- Collaborates with the care coordinator to facilitate meeting the client and family needs and expectations
- Provides educational resources for clients and families
- Advises on advanced care planning
- Collaborates with the team in the delivery of bereavement follow-up services for families
- Provides leadership in the evaluation of client and family outcomes
- Coordinates educational programs in collaboration with the team
- Contributes to the knowledge of the team by keeping current with the palliative literature

Palliative Care Resource Pharmacist

- Provides pharmaceutical care to ensure the drug-related needs of the client are met and drug related problems are prevented, and if not, identified and resolved
- Communicates the detection of any existing or potential problems in drug therapy to the physician and makes recommendations for alternate therapy
- Participates in weekly palliative care rounds
- Provides drug information to the team
- Contributes to the drug knowledge of the team through literature review
- Provides support and education to pharmacy colleagues in all care settings in the safe and efficient dispensing of palliative related medications

Palliative Care Resource Social Worker

- Participates in weekly rounds
- Provides counseling to clients and families who are experiencing conflict
- Provides adjustment, grief support and resource counseling to clients/families
- Refers to community supports and provides appropriate follow-up
- Provides support to client/family and to team members regarding children's grief/death issues
- Facilitates team to address their cumulative grief issues
- Contributes in education sessions to the community on palliative care issues
- Identifies community resources and develops strategies to meet community needs

Family Physician

- Responsible for the day to day medical management of the palliative care client in all care settings
- Provides medical assessment and intervention to palliative care clients
- Provides pain and symptom management in all care settings
- Collaborates with the interdisciplinary and resource team members
- Provides client and family with information and support to assist them in decision making and advanced care planning
- Participates at rounds for new referrals and complex situations as able
- Participates at client/family conferences

Intake

- Provides information to the public about the regional palliative care program
- Receives referrals to the regional palliative care program
- Provides an initial screening
- Initiates quick response as needed
- Collects baseline data and information
- Refers to the appropriate team member for the completion of the palliative care assessment
- Refers to other organizations as appropriate
- Provides statistical data

Care Coordinator

- Collaborates with the palliative care nurse in palliative care assessment process
- Collaborates with the client, family, and team in the identification of client/family needs and expectations
- Facilitates the development, implementation, and evaluation of the palliative care plan with the client, family and team
- Collaborates with the team in the development and monitoring of a resource allocation plan that reflects client's actual and potential needs
- Coordinates services in the care setting
- Communicates changes to team
- Attends weekly rounds
- Coordinates referrals for specialized services
- Coordinates medications and equipment
- Facilitates client/family conferences
- Coordinates transfers between care settings
- Provides statistical/ budgetary data

Nurse

- Provides timely pain and symptom management to palliative care clients
- Provides continuity of care with a designated primary nurse
- Participates in the initial and ongoing assessment of the palliative care client and families needs and expectation

- Provides comfort care measures
- Provides client/family teaching
- Provides timely communication to appropriate team members to ensure client/family needs and expectations are met
- Provides services as needed (may be intermittent care)
- Provides continuous assessment for clients who require monitoring for unstable pain and symptom management
- Supports clients and families in care decision making
- Participates in palliative care in-servicing
- Responsible for development, planning, and evaluation of nursing care plan
- Attends weekly rounds (supervisor or designate)
- Collaborates with the interdisciplinary and consultation team in meeting the needs and expectations of the client and family

Home Support Worker

- Provides family relief
- Supports family in preparation for a home death
- Provides emotional support and assistance to family immediately following a death at home
- Provides personal care to clients
- Provides meal preparation and feeding
- Provides emotional support to client and family
- Provides light housekeeping and laundry
- Collaborates with the team through ongoing communication verbally and in the chart
- Services when needed and intermittently

Community Support Worker (role in PEI only)

- Assists clients, families and other team members to access other resources in the community, i.e., Meals on Wheels, financial assistance, insurance plans, support groups
- Assists clients and families who have financial resources to hire in- home help by providing names, phone numbers, and references from a data bank of private service providers
- Assistance with the development of community resources if they are not available

Social Worker

- Provides counseling for clients individually and as a family
- Provides assistance with securing financial benefits
- Facilitates transfer from acute care to long-term care (Nova Scotia only)

Discharge Planner

- Collaborates with health care providers, client and families on complex discharge issues
- Attends case conferences in complex palliative care cases
- Facilitates transfer between care settings in complex situations
- Links with appropriate follow up services on discharge

Coordinator of Palliative Care Volunteers (paid and unpaid)

- Coordinates recruitment, screening, and training of palliative care volunteer
- Provides liaison between the team and the volunteer
- Matches clients/families with volunteers
- Provides leadership and support to volunteers
- Coordinates the bereavement follow-up
- Attends palliative care rounds
- Coordinates remembrance services
- Provides monthly and annual reports on volunteers activities
- Collaborates with the team in identifying client/family needs that can be met by a volunteer

Palliative Care Volunteers

- Provides emotional support
- Provides social and leisure support
- Communicates with the team through the palliative care chart
- Collaborates with the team in identifying unmet needs and expectations of client and family
- Provides bereavement follow-up as requested
- Provides support to family when death appears imminent, and immediately after their loved one dies

Pastoral Care

- Supports the client and family with spiritual needs
- Participates in bereavement care
- Participates in the remembrance services
- Supports and advises the team on spiritual issues as it related to palliative care, where there is a pastoral care person designated to participate on rounds

Pharmacist

- Provides prescribed medications in a manner that optimizes safety
- Provides pharmaceutical care to ensure the drug-related needs of the client is met and drug related problems are identified, prevented and resolved
- Communicates the detection of any existing drug related problems
- Educates client and family
- Ensures palliative care medications and supplies are available

Physiotherapist

- Provides assessment for and recommendations about treatment services to promote comfort
- Collaborates with the team in the development and implementation of pain and symptom relief measures
- Provides education to the client and family

Occupational Therapist

- Assesses client for specialized equipment to promote comfort
- Provides education to client and family
- Investigates and implements energy conservation techniques with the client and family
- Promotes maintenance of independence through the provision of aids and adaptations

Dietician

- Acts as a resource to team on all aspects of food and nutrition
- Provides education to the client and family on nutritional management, supplements and coverage

Respiratory Therapist

- Carries out treatment services to promote client comfort
- Works with other team members to facilitate appropriate home therapy
- Assesses client need for specialized equipment such as home oxygen
- Provides education for client and family

To support an integrated service delivery model an information needs assessment was conducted.

A full day facilitated workshop with service providers and program planners developed a comprehensive list of information required from an integrated palliative care program. Information technology consultants reviewed the service delivery framework and the information and reporting requirements of service providers and administration to provide the project with insight into systems requirements for an integrated palliative care program. The steps towards identifying IT requirements are:

- Identification of service delivery processes (model)
- IT considerations for each process
- Overview of information needs
- Overview of systems requirements
- Reporting requirements

A detailed description of the information needs assessment is available through the project contact.

The primary participants in the planning and implementation of the integrated palliative care program in the regions were home care, community nursing, palliative care consult/resource team, family physicians, social work, pharmacy, pastoral care, and palliative/hospice volunteer coordinators. However, in order to meet the needs of the patient and family at home a number of additional linkages to the palliative care program were developed. While these new programs are in their formative stages, some of the necessary external linkages are in preliminary stages of development and others are further along.

Emergency Health Services, Medical Examiners, and Funeral Directors

In the Northern Health Region, NS, Emergency Health Services (EHS), medical examiner's office and funeral directors collaborated with the palliative care team in the streamlining of processes to support an expected death at home. This joint development and subsequent education delivered to paramedics, family physicians and health care providers was viewed as a positive outcome. In PEI, this process occurred simultaneously as a provincial initiative.

Concurrent to program planning and development was the introduction of a new booklet *Planning for an Expected Death in the Home*, developed by the Nova Scotia Department of Health to assist families in planning for a home death. Although viewed by service providers as an excellent teaching tool, there were

systems and educational gaps creating barriers to a coordinated home death. Consequently, an ad hoc planning group of Emergency Health Services, funeral directors, medical examiner's office and palliative team members developed regional guidelines to assist in the support of an expected death in the home. In addition, continuing medical education (CME) sessions were delivered by a team consisting of regional medical advisor, emergency medical advisor, provincial medical director, Home Care Nova Scotia and the medical examiner's office to inform family physicians of the processes to support a planned home death.

In PEI, a teaching tool for planning for an expected death at home was developed by a working group representing such providers as funeral directors, medical examiners, home care and emergency response teams. This was facilitated by the Department of Health and Social Services in partnership with the Canadian Cancer Society. Preliminary evaluation of the tool indicated that it was cumbersome and oriented primarily to health care providers. Revisions were made in the demonstration regions and early evaluations report a more effective teaching aide for patients and families. Health and community systems were not seen as a barrier to support a planned death in the home.

Acute Care

In order to provide continuity of care for clients and families as they cross care settings relationships with staff in local hospitals were strengthened. Acute care staff attended the front-line education sessions and the regional palliative care teams invited key hospital staff, such as discharge planners or clinical leaders, to attend rounds. This was seen as a positive step towards facilitating communication among care settings, improving the process for admission to the palliative care program and towards timely and effective discharge planning from hospital to home for palliative care patients and families.

Other Palliative Care Programs and Health Care Facilities

Recognizing that clients and families in a rural community need to travel to other regions in the province as well as out of province for care and treatment, programs have begun building on existing linkages and establishing new ones outside their regions.

Oncology/Cancer Centres

Given that 80% of clients registered with the palliative care programs have a cancer-related illness linkages are already developing with oncology services in order to encourage early identification and referral to palliative care.

Long-term Care

Participants from the long-term care focus groups indicated the importance of linking to services outside of the facility when needed but felt that these links needed to be strengthened. To ensure that links existed between the palliative care teams and long-term care, palliative care advisory committees in all demonstration sites had long-term care representation.

The caregiver survey asked participants to identify and rate the helpfulness of health care providers involved in their care over the past two weeks. Those identified as most helpful were the home care/community nurse, home care coordinator, palliative care nurse, home support worker and family physician.

Table 8 provides a preliminary overview of available palliative care program costs based on days on the program. It does not include family physician home, office or hospital visits; outpatient visits for procedures, x-rays and laboratory tests; or equipment and supplies provided. It also does not include

other palliative care team members whose costs are absorbed into the global budgets nor does it include mileage or program support. The biggest contributors to cost are the inpatient days.

Table 8: Regional Program Cost Summary for Palliative Care Clients', February 21, 2000 to October 31, 2000

	Northern Health Region N= N=134		East Prince and Southern Kings Health Regions PEI N=20	
Cost Item	5375 patient days at home 82% of total days	1135 patient days in hospital 17% of total days	440 patient days at home 64% of total days	246 patient days in hospital 36% of total days
Palliative Care Nurse[1]	$143,500	$11,500	No funding	No funding
Palliative Care Physician[2]	$22,140	$4,500	No funding	No funding
Home Care Coordinator[3]	$103,320	$21,420	n/a	n/a
Nursing visits[4]	$70,771	n/a	$4,640	n/a
Home Support Worker hours[5]	$59,846	n/a	$2,600	n/a
Hospital days[6]	n/a	$567,500	n/a	$102,456
ER visits	$18,400	n/a	$1,870	n/a
Home oxygen[7],	$6650	n/a	No funding	n/a
TOTAL	$424,627	$625,070	$9,310	$102,456
Cost/day/patient	$79.00	$550.66	$21.16	$416.50

Cautions while reviewing these costs are the service gaps in the home to be discussed further in the report. They include:

- Medication costs
- The lack of program and service provider access after hours
- The need for increased respite
- The need for increased family physician involvement and appropriate reimbursement.

A Rural Palliative Home Care Model

While this cost analysis is preliminary it does appear that very ill patients and their families can receive good pain and symptom management and emotional support at home. The future challenge for health care systems is to continue to make the shift from hospital days to home days and as well to shift the appropriate resources.

Funding

Funding to develop and implement the integrated program came from the three demonstration sites regional health authorities, the participating provincial departments of health, and the Federal Health Transition Fund (FHTF).

- FHTF supported the developmental processes, the education development and implementation, and the project evaluation.

Nova Scotia

Funding to develop and implement the integrated program came from the Northern Health Region, Nova Scotia (NRHB) and the Nova Scotia Department of Health (DOH).

- NRHB hired additional palliative care consult nurses and utilized existing resources to enhance the pharmacy role. Two hospitals provided a social worker to the palliative care team, but Pictou County could not fund this position. In addition, two hospitals provide volunteer coordination.
- DOH provided funding for palliative care physician sessional fees, home care nursing, home support, medications (when there was a financial burden), and care coordination.
- Community supports are provided through the Aberdeen Palliative Care Society, VON Cumberland (volunteer program), service clubs, churches and many non-government organizations.

Additional costs absorbed by NRHB and DOH were data collection, program planning and supervision.

Prince Edward Island

Funding to develop and implement the integrated program came from Southern King Health Region (SKH), the East Prince Health Region (EPH) and the Department of Health and Social Services (DHSS).

- EPH and SKH utilized existing resources to enhance the nursing and pharmacy roles by providing time for client assessment and rounds.
- DHSS as well as the regions absorbed additional costs for program planning, supervision, and data collection.
- Community supports are provided through the Island Hospice Association, EPH Branch, SK Hospice Association, service clubs, churches and many non-government organizations.

AN OVERVIEW OF PROJECT FINDINGS

This overview will highlight the salient themes drawn from the tremendous amount of data generated by the project. Data sources were the project surveys and interviews administered to those clients and caregivers who agreed to participate as well as health care provider focus groups. A more thorough analysis of this data is available on request.

In addition, the three new regional palliative care programs provided their referral, mortality, and service utilization data collected between February 21'2000 and October 31'2000.

Key Finding #1 Seventy-six per cent of clients surveyed indicated their preferred place to spend their last days was at home. However, there remains a majority who die in hospital and who need to access hospital often through emergency departments to address their palliative care needs.

Time at Home

Programs reported that during the evaluation period, clients in the Northern Health Region, Nova Scotia, spent 82% of patient care days at home, and in PEI they spent 65% of their patient care days at home. However home deaths represented 32% and 40% respectively in the same region. Table 9 outlines the breakdown of days at home and days in hospital.

Table 9: Days at Home and Days in Hospital for Palliative Care Home Clients*

	Northern Health Region, NS (n=134)			East Prince and Southern Kings, PEI (n=20)		
	Days on Program	Home days	Hospital days	Days on Program	Home Days	Hospital days
Mean	49	40	8	34	22	12
Median	35	23	5	20	14	8
Minimum	1	1	1	4	1	1
Maximum	213	213	60	107	107	70

* This data excludes the 27 (17%) patients in the Nova Scotia site and 14 (41%) of patients in the Prince Edward Island sites, who spent all of their time in hospital while on palliative care program.

Utilization of Acute Care Services

A group of clients not evaluated for issues around palliative home care services are those admitted to the regional palliative care program who spent all of their final days in the hospital. This group represents 17% of program patients in the Northern Health Region and 41% in the Prince Edward Island sites.

Emergency Department Services

Regional program data reports of emergency room visits, support that this is often how problems are addressed particularly after hours. Program data reported that 43% of patients (n=67) in the palliative care program made an average of 1.3 visits each to the emergency department with a resulting admission. Cited reasons were medical emergencies (55%), pain management (10%), symptom management(31%), inability to cope(16%) and imminent death(18%).

A great majority of these visits are after-hours. In PEI 12 of the 15 patients who went to the ER did so after-hours. An audit conducted by health records at three hospital emergency departments in the Northern Region reported that 45 of 67 emergency room visits by palliative care patients were during after-hours.

Recognizing that emergency room visits are appropriate in a medical emergency, the number of non-medical emergency visits suggest that a gap may exist in the system's ability to problem solve after hours in the community without transferring the patient to hospital.

Direct Hospital Admissions

The hospital needs to be accessible when there is a critical role for complex pain and symptom issues, imminent death (when home is not a choice), and respite (in the absence of an alternate facility or hospice). Forty-three patients (30%) averaged 1.2 direct admissions to hospital for symptom management (33%), pain (28%) and imminent death (21%). It is not known what home intervention preceded the direct admission.

Furthermore, pain and symptom management as a reason for hospital admission was identified by the five interviews that were conducted with patients who were admitted to hospital while on the project. All respondents indicated that they had gone to hospital because they were experiencing pain and discomfort. However, all but one indicated that they would have preferred to stay at home if the appropriate supports were in place. Again, this raises the question of what assessment and intervention preceded admission.

When admission is necessary, direct admissions to an inpatient bed, not through the emergency department, is the recommended route of entry.

Transportation Issues

Another consideration regarding rural clients and hospital visits during their last days of life is around transportation. The average time to drive to hospital ranged from two to 90 minutes, with an average of 22.8 and median 15 minutes. In addition, only 55% had access to a car. Rural roads are bumpy, driving is slow in the winter, and uncomfortable for a physically vulnerable palliative patient. Avoiding unnecessary trips to hospitals would be recommended.

Access to Hospice Facility

There are no formal hospice facilities in the demonstration regions. It was identified in palliative care team focus groups that there is nowhere for palliative care clients requiring extended care or more constant supervision to go. This is particularly so if they are not eligible for a long-term care facility, and even if eligible, it may not be an optimal solution. It was suggested that a separate palliative care location is needed such as a hospice setting.

Some participating caregivers (n=25) noted in the past four weeks the person they were caring for required immediate service for:

A) uncontrolled symptom needing urgent attention (11)

B) medication needing urgent attention (9)

C) a needed procedure (8)

Caregivers indicated that these problems were typically quickly addressed, scoring an average of 4.19 out of a possible 5 (very quickly).

Caregivers were also asked as part of the evaluation to indicate whether they needed help during the night. Twenty-five percent (n=28) of caregivers reported requiring help for the person they were caring for during the night in the two weeks prior to completing the survey. Reasons cited were respite care (32%), assistance with medications (25%), and assistance with personal care (29%). The most common way the

caregiver handled the situation was by calling a non-professional (35.7%), emergency services (14.3%), calling a professional, hiring help or managing on their own (each 10.7%).

Key Finding #2 Individuals 65 years and over and individuals dying from cancer did not access palliative care services in proportion to the respective rate of mortality in the region.

Referrals to the regional palliative care programs in the demonstration sites were 280 clients in the Northern Health Region, Nova Scotia, and 55 clients in total for East Prince Health Region and Southern Kings Health Region, Prince Edward Island.

In the Northern Region, Nova Scotia, the 280 referrals in the nine-month period represent a 31% increase from their '97-98 referrals.

However, it is suggested in *Integrating Palliative Care in Nova Scotia, a Discussion Paper (Nova Scotia Palliative Care Working Group, June '98)* that 80% of cancer related deaths and 20% of non-cancer related deaths could benefit from palliative care services. Applying this calculation to the 1999 mortality data for the Northern Health Region, there should be approximately 615 referrals to the palliative care program a year. The Northern Health Region program has met approximately 60% of that goal.

The 55 referrals to the two new programs in PEI is viewed as a successful beginning considering there were no existing palliative care programs to build upon. Referral benchmarks have not been determined.

First Nations and Francophone Populations

Palliative Care services are equally available to all individuals regardless of their age, gender, national and ethnic origin, race, color, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction or family status. (Program Standards)

There were two minority populations identified in the demonstration sites: a francophone population in East Prince Health(EPH), PEI (population 3135), and a First Nations population in Northern Region, Nova Scotia (population 2300) The five francophone referrals represent 9.4% of the EPH referrals and the three First Nations referrals represent about 1.1% of the Northern Region referrals. Both are in proportion to their population size. However, where there were no mortality data available at the time of report further comparisons cannot be made.

Representation from both groups participated in the regional program planning. In addition, the palliative program brochure in EPH was translated into French. Both were considered essential for improving access.

Sixty-five years and over

In the Northern Health Region's 1999 mortality statistics, 81% of individuals who died are 65 years and over. However, palliative care referral data, represent this same age group as only 65% of the referrals. In addition, referrals from long-term care totaled 2 over a nine-month period. It appears that this age group is therefore not accessing the palliative care program in proportion to their representation in the mortality data.

When to refer to palliative care is a challenge identified by the long-term care sector. One per cent of the regional program referrals was from long-term care. In a recent Nova Scotia, Department of Health report *Palliative Care in Nursing Homes*, it is noted that long-term care residents have a need for pain and symptom management at the end-of-life. The report recommends that there is access to palliative care consultation teams for pain and symptom management and education for staff to address these same issues.

Diagnosis

The regional programs reported that 80% of patients who died on their palliative programs had a cancer-related diagnosis. Cancer of the lung was reported as the most frequently presented diagnosis, with 31% of all deaths. This was followed by cancer of the breast (5%), colorectal cancer (5%), cancer of the esophagus (5%), cancer of the pancreas (5%), kidney and bladder cancer (5%), then cardiovascular disease (4%) and neuromuscular disease (4%).

In the Northern Health Region palliative care program, the 125 cancer related deaths in the little over eight months, is a significant discrepancy from the 529 cancer related deaths in a 12-month period reported in the 1999 mortality census for their own region.

Key Finding #3 A major success was the overall satisfaction clients had with their care. Clients indicated that the symptoms that had the greatest impact on reducing quality of life are poor appetite, problems with breathing, pain and sleeplessness, fatigue, inability to manage the household, problems with future planning, lack of mobility and problems with decision making.

Client Needs

Regional programs identified that assessed needs on admission were symptom management (75%), psychosocial support (66%), pain management (58%) and caregiver support (25%). Based on the McMaster Quality of Life Scale (MQLS), physical symptoms reported as having the greatest impact on reducing quality of life by clients participating in the evaluation phase of the project were poor appetite, problems with breathing, pain and sleeplessness. With respect to non-physical symptoms (as defined by the original authors of the instrument) participants indicated the greatest impact on reducing quality of life was fatigue, inability to manage the household, problems with future planning, lack of mobility and problems with decision making.

Client Satisfaction

Overall clients expressed satisfaction with pain and symptom management. However, when asked about pain relief for the worst pain they had in the previous four weeks, patients indicated only moderate amount of satisfaction with the speed with which they obtained pain relief (mean score 4.5 out of 7). We do not

know what interventions were employed to deal with the pain - for example, whether the pain was dealt with at home or hospital.

Clients indicated greatest satisfaction with coordination of care (4.42 out of 5), the way tests and treatments were performed (4.37); and the doctor's attention to symptom management (4.35). In addition both interviews and surveys indicated a high satisfaction regarding the availability of the doctor and nurses. Some client/caregiver interviews indicated their family physicians would see them with little or no notice and make home visits. Both of these things were very much appreciated by clients and caregivers.

Overall, client interviews indicated that they had no difficulty getting in contact with services when needed.

Items that received lower satisfaction ratings related to information around the illness including time taken to make the diagnosis (3.89), receiving information about tests (4.08), family conferences to discuss illness (4.10) and information about side effects (4.12). A number of clients and caregivers indicated that the lack of information around their illness and test results was stressful and frustrating for them.

Timeliness of Referral to Meet the Needs

Survival times were considered an indicator of the timeliness of referral. The mean survival time of 49 days (Northern Region, Nova Scotia, n=134) and 34 days (East Prince and Southern Kings, PEI, n=20) should be interpreted as very preliminary data for new programs in transition.

Key Finding #4 Caregivers indicated a high degree of satisfaction with the care their loved one was receiving. Caregivers rated highest the need to have questions answered honestly, to be assured that the best possible care is being provided, to know what treatment the patient is receiving, to feel that the professionals care about the patients and to know what symptoms the treatment or disease can cause. Unmet needs rated the highest amongst caregivers were information about symptoms and to feel there is hope.

In addition, correlation analysis indicated that as the clients quality of life decreases, caregiver burden increases.

Caregiver Needs

The caregiver needs and satisfaction survey invited caregivers to indicate from a list of 20 needs the importance of each need to them and whether they perceived the need as being met. The results indicated that generally all 20 needs were important to a great majority of respondents (87.2% to 97.9%). In addition, caregivers rated their importance of the items between 8.48 to 9.91 out of 10.

Caregivers were asked to rate whether the need deemed important was being met or not. The five most commonly unmet needs and the percent of caregivers that identified this need as being unmet were:

To know when to expect symptoms to occur (32.4%)

To feel there is hope (20%)

To know what symptoms the treatment or disease can cause (17.9%),

To have someone be concerned with their (caregiver's) health (16.7%)

To be told about people who could help with problems (13.5%).

Caregiver Satisfaction

Overall, caregivers indicated a high degree of satisfaction with the care their loved one was receiving. Although still rated fairly high, items for which caregivers' expressed the least satisfaction were family conferences to discuss the patient's illness, time required to make an initial diagnosis, the way tests and treatments were followed up by the doctor, how thoroughly the doctor assessed the patient's symptoms, and the way the family was included in treatment and care decisions.

Caregiver Burden Issues

Caregivers were asked to indicate their level of caregiving burden in the past two weeks. Caregivers indicated an overall level of burden equal to the middle of the scale (35.68 out of 70).The reported level of client dependence was fairly high (11.13 out of 15). Caregivers reported a moderate level of stress (11.01 out of 20), but for the most part did not indicate a strong desire for more support (13.29 out of 35). Caregiver stress most manifested itself in caregivers reporting being physically tired, emotionally drained and stressed.

The Caregiver Burden Scale was completed by the caregiver at the same time the client completed the McMaster Quality of Life Scale and thus allowed an examination of the relationship between client quality of life and caregiver burden. Moderate correlations were found between the total MQLS score (r=0.46) and caregiver burden as well as the non-physical subscale score (r=0.49) and caregiver burden, indicating that as the client's quality of life decreases, caregiver burden increases.

Key Finding #5 Financial burdens experienced by some participants are caregiver's loss of income, costs of medication, equipment and supplies.

In total, 12 (22.6%) caregivers indicated that they lost or gave up income as a result of caring for the client. The estimated income loss ranged from $400 to $2400 a month with an average loss of $1,363/month. Additional expenses related to the illness of the person for whom they were caring for were medications (co-payments and unensured drugs), personal care items, transportation costs, over the counter drugs and food supplements.

Additional expenses related to the illness of the person they were caring for that were not covered by the health system or private insurance averaged $281/month with a wide range of $12 to $1665. Confidence in this estimate is not strong however because caregivers presented a wide range of responses in this category from nothing, to tissue paper to major equipment expenses.

In PEI medication and enhanced nursing and home support services were not provided. Health care providers identified there were potentially high costs for medications, home care (private) and respite. When there is a large number of prescriptions even senior's co-pay could prove to be a financial burden.

Medications

In PEI approximately 50% (n=20) of clients had access to a private insurance plan, 70% accessed Senior's pharmacare, and 10% paid privately for all medications while at home.

In the Northern Health Region the available data was incomplete for medication coverages and needs to be viewed as preliminary data to build on. It appears that only approximately 60% accessed senior's pharmacare, just less than 20% had access to a private insurance plan, and approximately 10% accessed cancer society and community services. In addition, eligible patients could utilize the medication entitlements available in the region to palliative care patients. Eligibility was a prognosis of less then three months and the client or caregiver's indication that medication expenses were a financial burden. No detailed financial assessment was required. Ten actually received this benefit between February 21, 2000 and October 31, 2000 at a total cost of $1702.

Interviews with client/caregivers after the medication entitlements were implemented still noted that some of the respondents in the Northern Region experienced hardship around the costs of medication and supplies. Further inquiry is necessary to determine why such a small number of clients received the entitlements.

Equipment

There are a variety of resources in the Northern Health Region to access for equipment. The Department of Health has a home oxygen program whose eligibility guidelines are based on specific clinical indicators. Palliative care programs reported of the 38 clients requiring oxygen 17 were covered by the Department of Health, five through insurance, four private pay, four through the Hospice Society and two through Veterans Affairs Canada. Hospitals are identified as a source providing items such as comfort mattresses, commodes, urinals, bedpans and incontinent equipment. The community continues to be a major support providing equipment such as hospital beds, wheelchairs, commodes and walkers.

In PEI equipment is coordinated through a central loan cupboard. This provides a central access point for health care providers and the community at large. It also provides quality control and inventory monitoring. The cost of oxygen for end-of-life comfort continues to be an expense for clients not ensured. There was no government home oxygen program in PEI to support the 5 out of 20 clients who required home oxygen. Three of these clients had to cover the cost privately and the other two accessed private insurance In addition, a number of personal care items such as incontinence pads, dressings and lotions represented substantial cost to clients and families.

Caregiver Burden

On a scale from 1 to 7, where 1 represents no burden and 7 represent heavy burden, the average overall financial burden of the illness to the caregiver and the person cared for was 3.18. Caregivers were also asked to indicate their worry about being able to afford medical expenses for the person they are caring using a 7 point scale, where 1 indicated "not worried at all" and 7 "extremely worried." Overall, the average level of worry was ranked as 2.75. How worried the caregiver was about medical expenses and the overall financial burden of the illness to the caregiver and the person cared for was strongly correlated ($r = 0.724$, $p < 0.0001$). In addition three caregivers noted that the person they were caring for had not been able to get medicine, medical supplies/equipment or health care services because they were too expensive. These findings suggest that financial resources to pay for medications and supplies are an additional worry which only compound dealing with the issues around the dying process.

Key Finding #6 The education curricula was identified as a fundamental component to the development of the integrated palliative care program. Funding allowed for maximum participation.

Resource Teams

The consult/resource teams identified that the training was essential for increasing knowledge, promoting team development, and gaining credibility among other health care professionals. The learning model provided intervals of formal learning with opportunities for immediate implementation in their practice. Surveys showed a significant increase in knowledge from pre to post tests with a modest increase on the retention test completed five months after the intervention.

Primary Teams

Where the front-line staff are accountable for the care of patient and family, the multidisciplinary team education provided them with an excellent foundation to further develop in their practice and utilize the support of the resource/consult teams. Results of the pre and post tests indicated an overall significant increase in palliative care knowledge for participants with both a clinical and non-clinical background. It was shown in the follow up results that both the clinical and non-clinical groups retained knowledge over a three-month period.

However, it was also noted that the home care coordinators who were going to assume designated palliative care caseloads needed additional education as the front-line sessions did not meet their needs.

LESSONS LEARNED

Evaluation Issues

Recruitment of participants to research projects in palliative care poses particular challenges. The patient population is a very sick one, often cognitively impaired and one that is commonly protected by well meaning caregivers, professional and otherwise. The problem this presents is twofold. It makes it difficult in any one particular study locale to have enough participants to reach statistically meaningful conclusions unless there are very large effects generated by interventions. Second, the ability to generalize research findings from the participating group to the larger palliative population may be problematic. Nevertheless, obtaining such data, as limited as it is to a smaller sub population of palliative patients provides us with data closer to the needs of these patients than if we study more stable patients earlier in their disease trajectory.

There are particular lessons to be learned in the context of conducting research in a rural setting. In the intervention regions we were able to use the developing program infrastructure to create a recruitment method. In the proposed comparison region no such structure existed. As a result we sought study recruiters from within the small communities scattered through the region. The ability for them to inform those who might refer potential participants required extra effort when no real benefit could be provided to participants in the region. Also, the potential number of eligible participants is fewer in rural areas and they must be recruited over greater geographic distances. Further to this, the public education strategy to inform people that the study is underway requires strategies across multiple small community sites. With respect to qualitative methods, we found it difficult at times to generate enough local participants to adequately fill a focus group (usually 8-10 people). This meant that methods had to be adapted to bridge key informant interviews and focus group approaches.

Finally, the need for adequate data collection to provide the necessary program evaluation information is a recognized challenge in community based health care delivery. Systems of hospital information infrastructures are well developed in comparison to community based care data. Without such information, we cannot make informed policy or program decisions.

As future studies are planned, the ability to conduct research interprovincially will need greater exploration in order to achieve adequate sample sizes. At the same time, provincial jurisdiction for health policy and program development as well as local community variances presents challenges to such inter-provincial study design.

Education Issues

Team members consistently reported that the educational curricula was both critical to development of the palliative care program and provided increased competence and increased confidence.

The collaboration of the regional working groups with education consultants in identifying the variety of educational needs throughout the region was viewed as an effective process. This multidisciplinary approach can ensure an over-arching regional education strategy that addresses the needs of all service providers, family, patients and community. This was also apparent with the identification of regionally based faculty that ultimately will assist in building the foundation of a sustainable education program in the regions. Outcomes are enhanced local linkages, team building and the development of leadership skills.

The integration of practice and theory was very effective. It has been well documented that practice without adequate educational preparation is inadequate, but it is also true that education without immediate practice applications will be of less interest and quickly forgotten.

Public Awareness

A gap in the education strategy was the lack (due to project time constraints) of public education. Palliative care and home care are relatively new health care concepts to the public. In the absence of any public expectations or standard for them to measure, it is difficult to accurately assess community satisfaction with palliative care services. The public needs to be made aware of palliative care philosophy, available services and understand their rights in relation to palliative care principles.

Development of an Integrated Program

Team members indicated that having designated personnel from the project facilitating the planning, development and implementation was critical. In addition, they indicated that the commitment of the broad base of stakeholders in the process was essential to effectively mobilize the necessary resources to develop the program.

The development of standards and a program model, as an initial step in the process, focussed participants on the patient/family. This enabled working group members to build a common vision outside their specific discipline and agency.

Staff Burden: Did We Demand Too Much?

Staff unanimously identified the need for a system to provide quality palliative care in the home and while their commitment to the goal never waned, the stress became apparent. The magnitude of changing roles; development of new relationships; the demands of the very difficult developmental work; copious amounts of documentation and data collection; the intense education sessions; compressed project timelines; *and* providing care to palliative patients/families created frequent tensions and frustrations requiring understanding and support.

In reviewing the process, staff suggested that new programs look to *adopt* a palliative home chart rather than *develop* it. In addition, the challenging development of the case management function should be delayed until a team has matured in their development.

Team building was identified as an outcome of the resource team education sessions. While the broader palliative team included others team members such as home care coordinator, pastoral care and hospice/palliative care volunteer coordinators, team-building strategies should be incorporated in palliative care training.

Lastly, future planners need to consider the tremendous amount of time involved to facilitate and support staff as they overcome some of the challenges and role changes inherent in the development process.

Future Directions

Several areas of inquiry have been identified in this project as needing future study. These include:

- Further detailed descriptions of what prevents discharge from hospital to home
- Further detailed descriptions of the night and weekend issues currently requiring hospitalization
- Identification of the issues underlying apparent 'delayed or late' referrals
- The investigation of why the elderly are not accessing palliative care services proportionate to the burden of illness in this age group
- Identification of the palliative needs of residents in long-term care
- Identification of the necessary interfaces for an integrated information system

- Identification of the costs in delivering palliative home care and further definition of benchmarks for palliative care
- Methodological research issues around the challenges of recruitment in palliative care research

CONCLUSIONS AND RECOMMENDATIONS

Key Finding #7 Early successes in the development of the integrated palliative care program were the creation of a common set of palliative care standard, a standardized palliative assessment tool, the palliative care home chart, a standardized bereavement care plan and a single access. In addition, the palliative care consult/resource teams and weekly interdisciplinary palliative care rounds were identified as having a positive impact in the planning and coordination of the complex care needs of clients and families.

It must be noted that the integrated palliative care programs in the three demonstration sites have been underway for less than a year. To their credit, the many early successes include:

- A common set of palliative care standards
- Improved communication amongst team members
- Palliative care teams meeting on a weekly basis to review palliative care plans
- Palliative care consult/resource teams
- A common standardized palliative care assessment
- A palliative home chart
- Single entry
- Standardized bereavement care plan
- Front-line education curriculum
- Resource team curriculum

Key finding #8 Significant gaps in service delivery were the lack of 24-hour access; lack of funding for respite and nursing services; lack of funding for palliative care resource/consult teams; lack of appropriate funding for family physicians for palliative home visits; and lack of an integrated information system.

One of the project goals was to identify barriers and gaps to delivering palliative care in rural communities. The principle barriers and gaps are:

- Older population (over 65) not accessing palliative care programs in proportion to their mortality rates
- Cancer patients not accessing palliative care programs in proportion to mortality rates
- Late referrals to palliative care, thus not meeting the client's wish to plan for the future
- Lack of 24-hour access to program and services
- Lack of funding for respite and nursing services
- Cost of medication and equipment
- Long distances for both client/caregivers and service providers
- Lack of public awareness

- Lack of funding for palliative care resource/consult teams that include a physician, nurse, pharmacist and social worker
- Lack of appropriate funding for family physicians conducting palliative home visits
- Inconsistent access to palliative education for physicians and interdisciplinary team members
- Lack of an integrated information system for data collection

The majority of palliative care patients want end-of-life care in their home when appropriate supports are available. Given the availability of a funded palliative care service, accessible 24 hours/day, patients and families will have a choice to remain at home. However, caregivers choosing to give up employment to care for a loved one at home are suffering the financial burden of income loss, added to the strain of being the primary caregiver. In fact the burden of cost often shifts from the health care system to the caregiver. Caregiver contribution should be valued through an income compensation program, and hence relieving some of the financial burden.

An essential component to the success of the integrated palliative care program was the funding provided for the development and evaluation of the integrated model, along with the education to support the implementation. While provinces and regions provided funds for various components of the model, gaps outlined in this report need to be addressed.

Health care initiatives in the year 2000 are greatly disadvantaged due to provincial fiscal restraints. At an even greater disadvantage is the palliative care population who because of their vulnerability are unable to advocate for themselves. Furthermore, as long as we remain a death-denying society, a wide sweeping social movement aimed at improving end-of-life care is unlikely. However, with the increase in our aging population and the projected rise in cancer related deaths, a health systems demand for end-of-life care is mounting.

A small group of rural Canadians in this study have provided a voice indicating they want their last days of life to be in their home. The challenge to mobilize the necessary resources to address end-of-life care rests with both the federal and provincial governments. It will be their values and their commitment that will dictate what quality end-of-life care to fund. The time to move policy is now.

The following recommendations target federal and provincial governments in the spirit of collaboration and partnership in order to support dignity in the last days of life for all Canadians.

Recommendation #1

Palliative care be identified as a core essential service with home identified as the preferred setting. Service elements will include:

- A coordinated and integrated network of services accessible 24 hours/day.
- Pain and symptom management, psychosocial and spiritual support, counseling for patient and family, family relief/respite and bereavement care.
- An interdisciplinary team of service providers that includes physicians, nurses, home support workers, personal care workers, volunteers, social workers, pastoral care workers, care coordinators, physiotherapists, occupational therapists, respiratory therapists, dieticians and other allied health professionals as needed.
- A palliative care consult/resource team with expertise in pain and symptom management and advanced care planning.
- A leadership structure responsible for program planning, administration and accountability within an integrated framework.

Recommendation #2

Funding of an integrated palliative care program should include planning, development, service delivery, education, evaluation and program support. Specifically, funding would include:

- A program development, education, and evaluation strategy directed by a program coordinator/manager.
- 24 -hour access to home care services that can address pain and symptom issues, respite and emotional crisis in the home for palliative patients and families.
- Palliative home care medications from a specified home care formulary.
- Appropriate reimbursement for family physicians providing palliative home care.
- Equipment necessary to promote comfort in the patient's home.
- Palliative care resource/consult teams including physician, nurse, pharmacist and social worker.
- Coordination of volunteer services.
- Coordination of bereavement services.
- An integrated information systems for assessment, care planning and evaluation.

Recommendation #3

A comprehensive education strategy addressing the learning needs of resource/consult teams, front-line staff, family physicians, volunteers and the public be an essential element of an integrated palliative care program across all care settings. Specifically, an education strategy would include:

- The funding to coordinate and implement an education strategy.
- The funding for palliative care resource team members including family physicians, to perform an educator role in their region.
- A provincial infrastructure for education to support the development and continuing education needs of the palliative care resource/consult team.
- The funding of a public awareness campaign to educate the public on palliative care philosophy and available services.

Recommendation #4

Palliative care residents living in a long-term care facility be considered as living in their home and have access to the full range of services within the integrated palliative care program. Specifically:

- Appropriate legislation and policy should support a dignified death.
- Palliative care resource/consult teams and long-term care agencies define the linkages with respect to care of the palliative care resident.

Recommendation #5

Regional palliative care programs strengthen linkages with tertiary centres and specialty populations to further expand on the integrated model. Specifically:

- Palliative care programs and regional cancer centres improve accessibility for cancer clients to palliative care.
- Palliative care programs and pediatric centres identify specific palliative care needs for the pediatric client in rural communities.
- Regional and provincial palliative care programs develop linkages to address complex pain and symptom issues, resource/consult team development and research.
- Palliative care programs explore linkages with diagnostic groups such as HIV, neuromuscular, respiratory and cardiovascular diseases.

Recommendation #6

Income assistance and job security be provided to family members choosing to care for a palliative patient at home.

Recommendation #7

A national evaluation strategy be developed that would incorporate research principles and an integrated system for data collection. Specifically, an evaluation component would include:

- Program data collection to help address current palliative care issues and allow for the integration of additional data collection for research purposes.
- A committee to develop guidelines and review applications for outside researchers to conduct research through the palliative program and to ensure that such research is conducted in an ethical manner that respects palliative patients and their families.
- Provincial or national guidelines be developed around standard information to be collected by all palliative care programs to allow comparison across programs.
- The establishment of a provincial, regional and/or national palliative care research centre.